

23 — 24 JUNE 2022  
INTERNATIONAL CONFERENCE



# PEDIATRIC CANCERS & GENOMICS: A GAME CHANGER?

Cross Perspectives Between Social Sciences, Medicine and Civil society



Amphithéâtre de Physique, Université Claude Bernard Lyon 1, Faculté de Médecine  
et de Pharmacie. 8, avenue Rockefeller, Lyon 8<sup>e</sup>

[cancerchildreng.sciencesconf.org](http://cancerchildreng.sciencesconf.org)





## Day 1 : Thursday 23 June

### 9h30-10h15 Welcoming

10h30- **Inaugural Speech – Sylvain Besle** (sociologist, CRCL, Dep. SHS CLB) and **Nadège**

10h45 **Corradini** (pediatric oncologist, IHOPe)

### 10h45- **Session 1 - Transformations of the frontier between care and research**

12h30 Chair: Quentin Lade (sociologist & historian of sciences, Dep. SHS CLB, SIRIC LYRICAN)

*Childhood cancers and precision medicine: issues and perspectives* - **Gilles Vassal** (pediatric oncologist, Gustave Roussy Comprehensive Cancer Center, Univ. Paris Saclay)

*Presenting the genomic activity of an oncopediatric department* - **Franck Bourdeaut** (pediatric oncologist, SIREDO, centre d'oncologie pédiatrique de l'Institut Curie, INSERM U830)

*Should we keep on separating care and research in the context of genomics?* - **Catherine Dekeuwer** (philosopher, MCF Faculté de philosophie, Univ. Lyon 3 Jean Moulin, IRPhil et SPHère - UMR 7219 et Univ. de Paris)

### 12h30-14h Lunch break

### 14h- **Session 2 - Access to Genomics Medicine: inequalities, teamwork between medical** 15h45 **specialties, new timelines of the disease**

Chair: Juliette Froger-Lefebvre (sociologist, Univ. Paris Sorbonne, GEMASS, SIRIC, CURAMUS)

*A patients association's perspective* - **Patricia Blanc** (president of *Imagine for Margo* association)

*Access to therapeutic innovation for Children, adolescents and young adults with advanced Cancer across Europe (ACCE project)* - **Solenne Carof** (sociologist, Sorbonne Université-GEMASS) and **Emilien Schultz** (sociologist, CEPED, IRD, Univ. de Paris)

*Living with cancer/predisposition: whole genome sequencing in pediatric oncology* - **Ayo Wahlberg** (anthropologist, Professor MSO, Univ. Copenhagen)

*Trajectories of innovation in healthcare: bioethical and societal issues, a paradigm shift in care* - **Sophie Julia** (geneticist, Génétique Médicale Hôpital Purpan CHU Toulouse, Inserm, UMR 1295, Equipe BIOETHICS)

### 15h45-16h15 Coffee break

### 16h15- **Session 3 - Political Stakes of Genomics Medicine**

18h Chair: Héloïse Pillayre (sociologist, Dep. SHS CLB, SIRIC LYRICAN)

*Professionals, associations and representatives: teamwork in favor of research and children with cancer's families* - **Stéphanie Ville** (*Aidons Marina* and *Grandir Sans Cancer* associations) and **Stéphane Vedrenne** (*Eva pour la vie* and *Grandir Sans Cancer* associations)

*Deploying genomic medicine in France through the 2025 Plan France Médecine Génomique* - **Frédérique Nowak** (coordinator Plan France Médecine Génomique 2025)

*Planning genomic medicine in France in the era of high-speed bandwidth* - **Catherine Bourgain** (sociologist, INSERM, Cermes3, CNRS UMR 8211, Inserm U988, EHESS, Univ. Paris Cité)

*Precision medicine delivery for paediatric cancer patients in the UK – current status, aspirations and challenges* - **Susanne GATZ** (Associate Clinical Professor in Paediatric Oncology Cancer Research UK Clinical Trials Unit (CRCTU), Institute of Cancer and Genomic Sciences)



## Day 2 : Friday 24 June

**9h-9h10** Introduction to Day 2: presentation of a thematic issue of *Anthropologie et Santé*  
– **Solenne Carof** (sociologist, Sorbonne Université-GEMASS)

**9h10-10h45** **Session 4 - Envisioning Consent: Children's and their Families' Information and Choice**  
Chair: Alexandra Roux (sociologue, Iris, Univ. Paris-13, Cermes3)

*Ethical guidelines and regulations of biomedical research on children: between autonomy and vulnerability* - **Maria Cristina Murano** (philosopher, Institut de recherche biomédicale de l'hôpital La Paz, Hôpital universitaire La Paz, Univ. autonome de Madrid, SPHERE,CNRS-Univ. de Paris)

*Practices of pediatricians and interns in pediatric oncology: consent to research and communication of genetic information to parents and child – Conect-aml project* - **Arnaud Petit** (pediatric oncologist, Hopital Trousseau) and **Audrey Guilmatre** (clinical research engineer)

*GeneInfoKid project: psychological and ethical issues identified during the interviews and focus groups with parents and children* - **Marion Droin-Mollard** (psychologist, APHP) and **Sandrine de Montgolfier** (epistemologist et ethician of biomedical sciences, SESSTIM, Aix Marseille Univ./IPC)

*How to talk to children in an oncogenetic consultation* - **Béatrice Claret** (psychologist, IGR)

**10h45-11h15** **Coffee break**

**11h15-12h45** **Session 5 - Data collection, conservation and re-use: juridical and ethical rules of genomic medicine**  
Chair: Marie Castets (biologist, CRCL)

*Reflections of parents' associations around data legal and ethical issues* - **Catherine Vergely** (ISIS-Unapecle association)

*Let's not forget the rights of children in oncogenetics: what the law says, or does not say...* - **Emmanuelle Rial Sebbag** (lawyer, CERPOP, UMR1295, Inserm/Univ. de Toulouse Paul Sabatier, team BIOETHICS, CERPOP)

*International discussions regarding return of results and secondary findings, leading to questions of re-analysis, duty to recontact, and consequences for family members* - **Pascal Borry** (professor of bioethics, Centre for Biomedical Ethics and Law, Dep.of Public Health and Primary Care, KU Leuven)

**12h45-14h30** **Lunch Break**



14h30-  
16h15

## Session 6 - Seize and Collect Sick Children's voices

Chair: Solenn Thircuir (sociologist, Univ. Claude Bernard Lyon 1, Dep. SHS CLB)

*Intergenerationality in the Pediatric Cancer Ward: Age-Based Power and the Production of Data about Children's Voices* - **Anthony Wright** (anthropologist, assistant Professor of Childhood Studies, Rutgers University)

*There is no such thing as silence: Examining when young people with cancer do not talk (and neither do adults around them)* - **Ignasi Clemente** (anthropologist, assistant Professor, City University of New York)

*Capturing the experience of children with cancer from the first signs of the disease to post-cancer: issues and methodology* - **Hélène Lecompte** (sociologist, SPHERE UMR INSERM 1246)

*Between personalized medicine and medicine for the individual: the care of adolescents and young adults with cancer in France* - **Thibaud Pombet** (sociologist, Institut Catholique de Paris, RCS, Cermes3, Lirtes)

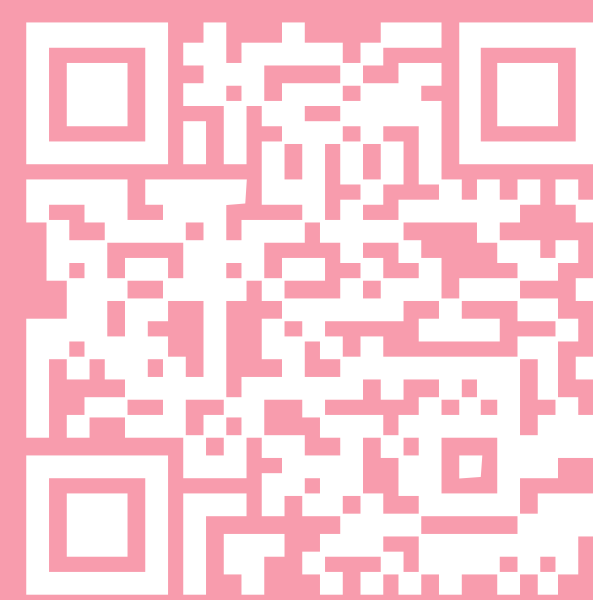
16h15-16h30 **Conclusion** - Sandrine de Montgolfier

International conference with simultaneous translation (English/French & French/English)

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### Location: Lyon, France

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